

IQECAD STUDY

Information Document (for children aged 12-17 years)

IQECAD stands for "Initiative for quality improvement and epidemiology among children and adolescents with diabetes". It has been running since 2008, and collects medical information about patients who have diabetes, like you, and who are treated in recognised diabetes centres in Belgium. It is being run by Sciensano, rue J. Wytsman 14, at 1050 Brussels, which, with the RIZIV-INAMI, fulfil the role of data controller.

Before you decide whether you would like to take part, please read this document.

Why are personal data collected?

The IQECAD is used to support medical research and to improve the quality of care and the treatment of patients with diabetes.

It has various objectives, here are a few examples:

The IQECAD studies the epidemiology of the disease (e.g. how many patients have diabetes in Belgium, what complications they have, what treatments they receive etc.). The IQECAD also uses data to improve the quality of care in the centres where the patients are treated. Researchers can use the data from the IQECAD to conduct studies.



What personal data will be collected in the IQECAD ?

The IQECAD collects general data such as your age, your gender and your age when you were diagnosed. It also collects clinical data such as weight, height, complications linked to diabetes and the medical examinations you have had over the course of the year, as well as the treatments and medicines that you have received but also information related to your well-being.

All of these data come from your medical file or the National Registry and are recorded by the doctor and the care team in the centre where you are being monitored. Besides, every two years, during a period of 7 months, you also have the opportunity to answer a personal questionnaire on your well-being via a secure web survey (5 mins to complete). During the collect period you can fill out the questionnaire several times if you need to (before each consultation with your physician for example. Your name will never be given to the IQECAD . It is replaced by a code.



Protection of the database

The recorded data is sent and stored in a completely secure way, on a platform called Healthdata.be. The data is only be accessible to people who have been given authorisation.

Who has access to the data and how will the data be used?

The Group of Experts, represented by the doctors in the centres, the scientific collaborators from Sciensano and members of the college of doctor-directors for INAMI/RIZIV (the Belgian National Institute for Health and Disability Insurance) always ensure they only collect essential data that could improve the care and health status of patients with diabetes. Any use of data for a scientific project or another project always requires approval from this Group of Experts.

In the centre where you are monitored, the doctors and care staff who help them, have access to

all of the data that they have entered into IQECAD. The researchers only have access to coded data, i.e. data that wouldn't make it possible to identify you.

A report is published after every collection of data and this is available on Sciensano's website:
<https://www.sciensano.be/en/search/site/ipqe-ead>

Participation and Rights

There will be no costs linked to participation in the IQECAD for you and your parents or guardian. Participation in the IQECAD is entirely voluntary. In other words, you don't have to take part. The decision to take part in the IQECAD or not, will not affect the medical care you receive. You have the right to change your mind about your decision and to end your participation at any time. From that point on, your data will no longer be sent to the IQECAD .

However, data concerning you that have already been transmitted to IQECAD before the end of your participation cannot be deleted. This data is essential to support medical research and improve the quality of care and management of young patients with diabetes. The processing of this data may also not be limited.

If you want to view or correct your data, your parents/guardian can submit a request to the doctor responsible at the reference centre where you are treated.

Validity of Consent

This form, which you sign along with your parents/guardian, is valid until your 18th birthday. When you turn 18, your doctor will ask you to sign a new informed consent form yourself.

If any important changes are made to the IQECAD project, you will always be told and we may ask you to sign a new consent form.

For more information

You can find information about IQECAD on Sciensano's website:

<https://www.sciensano.be/en/projects/initiative-quality-improvement-and-epidemiology-children-and-adolescents-diabetes>

If you still have questions about the IQECAD, you can ask the care team.

And if you agree to participate in IQECAD, you and your parents/guardian can sign the informed consent form.

Thank you very much!!!

